HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Registered Charity No. 1109398

Issue 37 – February 2016

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

HSP can't stop me!

Amber in action
on the slopes

It was nearly two years ago now that I first discovered the world of adaptive skiing.

My HSP had progressed to the point that I could no longer ski standing up, (it first started causing problems for me in 2012, when I was 13, although I had shown signs since the age of 2, I am now 16) and I was looking for something new to try, to take the focus away from my disability. I found the charity Disability Snowsport UK online, and I had my first lesson in the monoski just before the 2014 Winter Paralympics. Although it was difficult at first, I fell in love with skiing in the sit-ski, and had many more lessons.

To further my skiing, it became apparent that I would need my own monoski, as these are made specifically to each individual skier, unfortunately, as with all adaptive equipment, this was very expensive. To overcome this barrier we held a number of very successful fundraising events, including a 5Km run (which I did in my wheelchair), cake sales, and coffee mornings (as well as one cake sale to raise money for the HSP Support Group), and last November I received my own monoski (which is sometimes referred to as ‘the beast’). I am very grateful to everyone who participated in these events, as well as the charities who gave me grants towards equipment costs. We will also continue to do fundraising events for the continuation of my skiing career and for the HSP Support Group. Recently my Grandfather, who owns F P Gaunt & Sons Funeral Directors, held a memorial service for their clients and raised money, which we will be sending to the HSP group.

My own monoski arrived at just the right time, as last September, I was spotted by the performance director for what was then known as the British Disabled Ski Team (it is now called Para-Snowsport GB) and invited to train with the team in October. This was very last minute planning, as it was only a few weeks away, and my monoski had yet to arrive, but luckily the order was rushed through, and I made it to Austria to train with the British team. This was a great experience for me, as it was my first time in the monoski on a real mountain, and I learnt a lot during this week, both in skiing skills and in how to take care of all my equipment properly. It was also very good to be around other young people with disabilities, as they understood what it was like, and it was good for me to see how they did things.

My next trip was to Landgraaf in Holland, for my International Paralympic Committee classification. For those not familiar with the world of disability sport, athletes are placed into different classes depending on how their disability affects them, and this affects whom they compete against, or how much times are altered to ensure the competition is fair. For me this involved assessment of my gait with my walking frame, tests for range of movement and spasticity, and a test of my sitting balance where I had to sit on a wobbly board and try and move side to side. Following this I was told that my classification was LW12.1, which means I have some leg and hip function (but not enough to ski standing), and mildly affected trunk function.

However, to confirm this result, the classifiers wanted to see me race, this was an interesting and unexpected decision for them to make, for I had never done any proper race training (my first time skiing a slalom course was the day before the race), and I didn’t yet have the appropriate protective clothing to ski as fast as I would have liked. Despite this, for my first race, I did really well, and won a silver medal for both myself and Great Britain. I came home feeling very proud of myself, especially as I wasn’t supposed to have been racing at all!

Amber proudly wearing her silver medal

Since then my skiing has continued to progress, I train twice a week at the Chill Factore in Manchester, and get to the gym as much as I can, I can’t wait to start racing properly, and I have high hopes for the future. If anyone would like to follow my progress or ask any questions, they can visit my blog at www.ambermeiklejanneyskier.blogspot.com

Amber Meikle-Janney

Chairman’s Column

I know I’m very late in saying this but Happy New Year to you all. I hope none of our members have been affected by all the severe flooding that we’ve seen on the news recently. It’s been very wet down here in Dorset but although I live close to a river, so far there has been no severe flooding. On a plus side, Spring seems to have come early and now I have daffodils flowering, I can confidently predict that this is going to be the first year ever that I have managed to enjoy at least one plant in flower on every day of the year.

I’m still enjoying my horse riding every Friday morning with Riding for the Disabled. In the process I have made some great friends which I certainly wasn’t expecting and without doubt it’s the best physiotherapy that I can get. Riding for Disabled is a charity run by volunteers with riding expertise that allows people with disabilities to enjoy horse riding at discounted rates. Further information can be found at: http://www.rda.org.uk/

You will read in this newsletter that there are some interesting and challenging fundraising activities taking place in the near future. I can’t thank individuals enough who take the time and effort to raise useful funds for HSP. I would like to particularly thank Peter Bateman from Porthcawl for all his hard work over the last few years selling pens and keyrings. Peter has now raised an amazing £9,000 for us and the money continues to accumulate.

We’re now able to provide a running shirt or polo shirt for anyone who’s participating in an event for us and I’ll certainly offer similar for the brave individuals who are about to do extremely long walks on our behalf. One individual who isn’t featured in this issue is a barman at my local pub, The Old Thatch. His name is Will Watson and he is going to do the three peaks challenge in Spring with a friend, to raise funds for HSP.

We’ve even received funds from a member who agreed with some family members that Christmas presents that no one needs wouldn’t be sent and received, and the money saved would be donated to HSP. Thanks Hilary.

Last Saturday night I was invited to The Amberwood public house in Walkford near New Milton on the Hampshire/Dorset border, to be presented with a cheque. They have been fundraising for HSP for the last 12 months with the aim to support local individuals affected by HSP. I was amazed to be handed a cheque for £2,275. On behalf of all members of the HSP Support Group I’d like to thank staff and customers at The Amberwood and particularly the landlady and landlord, Gill and John McEwen.

We have agreed with the Amberwood to use this money to help two teenage sisters from Portsmouth to purchase custom made RGK wheelchairs. I’d like to thank Carole Moore for her help with this and taking the trouble to visit the family concerned and discussing with them the support we were able to offer.

I am in the process of organizing a Music Festival to raise funds for HSP. Originally it was planned to stage a three-day music festival but it has now been decided to make it a one-day event on June 4th. This will take place at a local community farm which employs disabled individuals and half the funds raised will go to the farm. The farm is called High Mead farm and our intention is to call it the Potato Pants Festival. I’m hoping it becomes an annual event.

I’d like to thank Debbie Orme for volunteering to provide me with some assistance. For future newsletters, Debbie is going to communicate with all the regional coordinators and obtain all the information for me regarding local meetings. Having all this information given to me on one piece of paper will certainly make my job a lot easier.

I've booked the AGM for June 25th at the usual venue in Leamington Spa. It is my intention to stand down as Chairman this year as I have now been in the position for six years and I believe new blood and consequently new strengths and ideas, is required. I do hope someone comes forward and offers their services to fill the position. I intend to continue compiling the newsletter and to remain as membership secretary.

I look forward to seeing many of you at either the AGM or the Ashburton meeting in April.

Ian Bennett

HSP Group Grants

Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Adam's Column

Depression is one symptom that people with HSP can suffer from. I was talking with a friend who had recently had depression and was telling me about a tool he used with his counsellor. I thought I would share in case it may be of use to others. You can read this in more detail on my blog:
http://hspjourney.blogspot.co.uk/2016/01/depression-and-assessing-yourself.html
The tool allowed him to work out what his values were and then identify how different values are met in different areas of his life. Finally he assessed how well he lives to his values, providing a route for improvement. It is my thought that people may have values met with physical activity. This combined with the progression of HSP might mean gradually not being able to live in line with those values. For example, a person who values completing tasks to a high quality with a physical/mobile job will be aware that changes (or potential changes) in mobility might change the way they undertake their work, and affect their values.
The first thing which you need to do is to understand your own values. There are plenty of ways of doing this,
https://www.mindtools.com/pages/article/newTED_85.htm
and another at the beginning of the link in next thing to do, below.
The second step is to place these values into a "bulls eye" - page 2 of this link:
http://www.thehappinesstrap.com/upimages/Long_Bull's_Eye_Worksheet.pdf
The bulls eye splits life into four areas:

- work/education,
- relationships,
- personal growth/health,
- leisure.

Each of your values should be linked to one (or more) of these areas. This splitting of life into areas might cause you to alter or think of more values, and that is fair enough - you're simply trying to describe yourself. The important thing is to be honest and to have "something" in each sector.
Next, you score each value (or each area) by putting an X close to the centre if you are living fully by the values for that area and close to the edge if you are acting inconsistently with those values.
The "clever" part is then thinking about those values which are close to the edge and what you can do go get them closer to the centre. This may be a hard question, but my take is that you need to find a different way meeting the same value(s). You could do one or more of these things:

- Re-focus so that you spend more effort in the areas of your life where you already live by your values
- Find a new/alternative way of doing the same thing to get the same result
- Move yourself from the "do-er" to the "trainer" and transfer your values onto others

- Take up a new hobby/activity/job/career to get new stimulation
- Stop doing some things and move away from the consequent problems

There are probably other approaches you can take, and if that is the case do let me know! You may wish to do this in personal reflection, by discussion with someone you trust, or indeed by writing about it in a blog!

Further reading:

Kathy Charmaz, Loss of self: a fundamental form of suffering in the chronically ill. This describes this "problem" in the general context of chronic illness. There are some obvious parallels between what she writes and experiences with HSP.
http://qmplus.qmul.ac.uk/pluginfile.php/158532/mod_book/chapter/3334/Charmaz%20K.pdf%20
For mild depression you could alternatively read about a workshop I attended in 2014.
http://hspjourney.blogspot.co.uk/2014/04/stress-and-mood-management.html
This gave an outline of Cognitive Behavioural Therapy (CBT).
If you are taken by the values and that way of thinking about things you could read Stephen Coveys "The seven habits of highly effective people".

And Finally…..

People may like to know that Lego have now made a character in a wheelchair. I saw this on the internet:
http://www.bbc.co.uk/newsbeat/article/35429774/lego-reveals-new-disabled-figures-after-an-online-campaign
but it seems that you have to wait till June before you can buy it!

Adam Lawrence

Members without internet access

Hello fellow members.

Recently, I have had quite a few members of the HSP group asking for information/help with the PIP application form and other benefits. Many of whom have already completed their forms and sent them off. Had received a reply, which was not pleasing, hence the need to appeal the decision.

A lot of members have internet access, which is a bonus as we can give links and information regarding the question asked, so that the member can look it up and go from there. Those that do not have any internet access are limited as to information gained. We appreciate that it is difficult to get out and about, to gather such information.

Some general tips

Write down a diary for a week, explaining daily struggles that are encountered on any one day. Everything. Do not miss out information. This can be demoralising, but necessary, to allow the person reading your application to understand your medical condition.

Get together any letters, documents or other from medical professionals. Diagnosis, OT equipment given to make your home and yourself safe, Medication slip, Wheelchair service equipment, physiotherapist and any other medical letters that explain the difficulties you have with mobility.

Make copies of all. Only send the originals, if it is requested.

When filling out your forms, write your answers as if you are having your very worst day. This is what they need to know. Many write what they can do. Which can cause misunderstanding and stress, if the result is not as hoped.

If you have a care assistant, ask them to help you fill in the forms if necessary. They might have other suggestions.

Citizens advice bureau can help you with contacting relevant services and information in your area.

You should receive information with your application forms. I know it can be boring!!! But it can be useful.

REMEMBER: The support group is here to help & support members.

All contact information will be at the bottom of the Newslink.

If you do not ask, we cannot help.

Wishing you all success and as little stress as possible.

Della Brookman Region three

Volunteers Required

Web Site administrator

The HSP Group web site holds information about the condition and about the HSP group.

A Web Site administrator would need to do some or all of the following:

Make changes to the information on the system.

Backup the system at regular intervals

Be able to restore the system from a backup store

Become familiar with the system and add new items from time to time.

The web site is at present maintained within Joomla - which is a "Content Management System" or CMS.

This is on a remote server, and is accessed via an easy to use interface.

Database Assistant

HSP holds information on its members in a database.

The management of the database is largely done through a software membership program written by John Mason, the current Treasurer.

A Database Administrator would have the following duties:

Backup the database at regular intervals

Be able to restore the database from a backup

Become familiar with the software and debug the membership program

Add new facilities as required by the membership secretary.

Access the database with phpAdmin or similar to inspect/change database records.

Add/delete authorised users from the database

The program is written in PHP and Javascript
The database is MySQL hosted on a remote server

Wales Walk

I am the son of a member of the HSP Group called Kay Freeman and I will be doing a long walk in March/April. A group of us will be walking Offa's Dyke which is 180 miles long and runs from north to south Wales as shown below. We are aiming to complete this in 8 days due to different ages taking part. I decided to start this after meeting people at the HSP meeting in Ashburton when I dropped my mum there for a regional meeting at the Dartmoor Lodge Hotel.

We're aiming to finish the walk by the 3rd April. The route is Prestatyn to Chepstow along Offa's Dyke, exact numbers of participants are unknown at the moment but myself, John Sullivan, Hazel and Neil Wheeler and Pam Carver will definitely be taking part.

http://uk.virginmoneygiving.com/…/showFundraiserProfilePage…

Derek Weeks (Kay Freeman's son)

Long Hike for HSP

I'm undertaking a sponsored walk from Land's End to John o'Groats, including Ben Nevis, over a period of a month starting on the 21st May- 21st June 2016 (the longest day, when I should hopefully get daylight all day for 24hrs).

I first met Ian Bennett 35 years ago when we both worked at Flight Refuelling Ltd in Dorset on the same turning section on the shop floor. At the time Ians' mum was very unwell, with what turned out to be HSP, and I was unaware that it was a hereditary condition that was likely to be passed down to future generations.

After I had moved to Scotland, a number of years had passed before I became aware that Ian was suffering from HSP. It was recently that Ian asked me to attend a local fund raising event at Wooburn Green, near to where I was working at the time, and I was surprised to see how many people attending the event were suffering from this condition. It was at this time, I thought that whilst I do a lot of hillwalking, and instead of doing it for myself, it would be good to help the support group in its efforts to support its members.

During the walk, I will do two 100 metres Potato Pants legs (once in England, once in Scotland) to help raise awareness of the support group and its activities.

http://uk.virginmoneygiving.com/StuartMontrose

Stuart Montrose

Members' Letters

That immeasurable psychological ascent

A recent independent holiday trip to London took me to the wonderful Tower Bridge Experience, that is readily accessible to the likes of us since its re-opening with high level glazed walkways for downward viewing of its bascules and the Thames 138ft below. Then to Sir Christopher Wren's magnificent St. Paul's Cathedral that I hadn't seen since when, as a child, my mother had thought it was unwise to climb to the higher levels. Over fifty years on, I was back to reassess the position.

I must say emphatically at this stage that my subsequent safe assent was fundamentally dependent on the capacity of my shoulder musculature that I have gradually developed since being issued with elbow crutches in March 2009. This unplanned and, at times, uncomfortable development has provided me with the spontaneous capacity to correct imbalance and, accordingly, the means of moving me bodily in a controlled manner, though somewhat more slowly than conventional walking.

My inclination was to photo' the Millennium Bridge from a high level and then complement that with another, later on, of St. Paul's from halfway across the bridge. Undeterred, slow progress up the 257 regular wooden spiral steps found me in the Whispering Gallery, nearly 100ft up, having been very careful always to have regained my balance at a higher level before pulling up the crutch behind me. It goes without saying that prevention of falling backwards is vital for both us and those behind. Halfway around the Whispering Gallery another open doorway revealed a much more confined, well maintained, steep stone spiral staircase up another 119 steps to the Stone Gallery, that is an external walkway around the foot of the great dome. Firmly gripping the steel handrail with my left hand and pushing firmly down on my right crutch to lift me up each step, I eventually made it after allowing the queue behind me to pass three times.

With mission accomplished a few photo's later, I then began my descent on a separate but similar anti-clockwise spiral. Resolutely grasping the handrail in my right hand, my right crutch was dragged down hanging loosely from that forearm and the left crutch used with the handrail to lift me bodily down each consecutive step. A young overseas visitor ahead was seemingly concerned at my plight and, needless to say, somewhat alarmed when the right crutch broke loose from my forearm to clatter down ahead of me. She returned it to me, not to be seen again. My descent from the Whispering Gallery was thankfully gravity aided and uneventful except that on at last reaching the bottom, tears just welled up in my eyes at what had been achieved.

I feel that despite my safe return to terra firma, many a reader will view this whole escapade as grossly irresponsible. On solely human judgement so it would certainly seem, but when our judgement is open to be guided and fortified by our Maker, I never once feared the outcome. From this and past experience in unusual settings, I have absolute confidence that His grace is sufficient for us. For His power is made perfect in weakness. He knows perfectly well the psychological benefit that such an experience has undoubtedly given me and, moreover, is available to others who don't scoff at the assurance he offers. Constraints we do certainly have, but what the future may hold I find positively exciting! In our circumstances, such a positive frame of mind is of immeasurable value. So, from my own state of despondency a decade or so ago, this physical ascent will for me always remain 'that immeasurable psychological ascent'.

John Moule Region 8

Dear Ian,

Your work for us HSP'ers and your personal references to the Squatty Potty foot stool and Walnuts have been a great help for me. The specialist at Queens Square (Bowel Department) was very sympathetic but mentioned neither and said "It will get worse-give me a ring later."

Jane and Michael Bennett and their bi-annual meetings have been especially helpful (she is a treasure) and I heard there about FES for two feet and micro-stim.

HSP and life itself is completely subjective but thanks to my parents I have had the benefits of good education – King's School Rochester and College of Estate Management.

I have enjoyed Rugby, Squash, Snooker/Pool and have adjusted my life style to suit the ongoing disability. I took up Croquet and of course played Bar Billiards. I was persuaded to go Bowling and played outdoors for about 20 years. First I used 1 stick then 2 sticks with pads and for the winter season we played indoors until recently in a wheelchair. It was obvious that bowling outdoors especially in wet weather was too difficult.

My daily routine has now adjusted to take account of increased fatigue and bursitis on the elbow which I knocked when I lost my balance and fell on the driveway. The spasticity on my right leg has tightened so I take 3 Tizanadine a day and 6 large glasses of water. My ankles ache and my feet are swollen.

Breakfast at about 8.30 with prunes, all-bran and linseed, pancake, 2 cups green tea. 1 Tizanadine 1 Ibuprofen 1 Bisoprolol (heart) and enjoy back to bed till about 11.30 ish.

I recommend Avocado and fresh Pineapple as excellent fibre. Lunch is usually peanut butter sandwich and various bits from the fridge such as coleslaw, tomatoes, beans and vinaigrette, apple dark chocolate biscuits, cake and 2 coffees. I take 1 Furo water pill which means I go to and fro the loo. The afternoon is Computer and Duolingo French, a free course which I find engaging.

(Il faut que always requires the subjunctive)

Supper 7.00 'ish +1 glass of red say Riojah or Malbec. We watch TV or read until News at Ten, then 2 Tizanadine, 1 Paracetamol, 1 Hytrin (for Prostate)

I sleep until about 3.00 and take a Paracetomol. The 2/3 trips to the loo at night are of course a struggle/battle, but this is another change to get used to.

I have not been out since October but am hoping to revive!

Best regards

Michael Jarvis Region 1

Regional News

East Anglia Colchester Meeting

We met on Sunday, 11th October, for the second time at Feering Community Centre which is just a minute or two off the A12 in Essex. There were plenty of regulars as well as four people who are new to the HSP Group.

There was quite a hubbub over the tea cups except when we broke to have a more general discussion. We talked about the objectives of the HSP Registry as most members had been unable to make it to the AGM in the summer. Quite a number of members are still without a genetic diagnosis and others were particularly interested in being on the Register in case there might be a chance of taking part in clinical trials in the future.

Members enjoying getting together at the Feering Centre

Stephanie Flower told us about a recent procedure she had undergone to have a spinal cord stimulator implanted. She explained that despite regular attendance at the National Hospital for Neurology and Neurosurgery's Pain Clinic, the pain relief had been insufficient and so she had been given the opportunity to have a spinal cord stimulator implanted. It is an extremely costly procedure making it necessary for Stephanie to try an external device first, in order to establish whether or not the technology would provide relief for her. The trial was successful and she now has the implanted version which involves inserting a pulse generator battery under the skin and connecting it to wires inserted into the epidural space of the spinal column. She told us that it works rather like a TENS machine in that it blocks the transmission of pain sensations along the nerves to the brain. Recharging the implanted pulse generator battery is done through the skin via a pad placed over the site of the battery. It takes about 2 hours and the recharger itself, which is battery operated for convenience of use, has to be recharged from the mains. At present, very few spinal cord stimulators are being implanted because of the cost.

We then discussed other forms of pain relief, physiotherapy and exercise before finding that we were running out of time!

We shall be meeting again on Sunday, 20th March 2016 from 3.00 – 5.00 pm at Feering Community Centre, CO5 9QB. Everyone is very welcome.

Hilary Croydon

Forthcoming Events

Region 7 Meeting Birmingham

Saturday 12th March, from 12-3pm
The Kenrick Centre, Mill Farm Road,
Harborne, Birmingham, B17 0QX
Contact Penny Cohen: 07818 288 738
Email: pennycohen57@hotmail.com

Region 4 get together

Saturday April 9th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

Afternoon tea Regions 1 & 2

Saturday April 23rd 3pm – 6pm
The Clockhouse Milford
Call Jane Bennett on: 020 8853 4089

Norwich Meeting

Saturday March 12th 2pm
The Oaks Restaurant,
Premier Inn, Norwich Airport
Call Barbara Jones on: 01603 423 267

Colchester Meeting

Sunday, March 20th 3-5pm
Feering Community Centre
Feering, Essex, CO5 9QB
Call Hilary Croydon: 01284 728 242

Region 3 Meeting

May 21st 1.30pm – 4pm
The Orange Tree Public House
100 Stevenage Rd, Hitchin, SG4 9DR
Contact Della Brookman: 07710 637 941

Region 9 Meeting

Saturday 9th April, 2 - 5 pm
Meeting Room, St Helens South Premier Inn
Eurolink, Lea Green, St Helens, WA9 4TT
Call Irena Pritchard on 01524 261 076

HSP Support Group AGM

Saturday 25th June
Trident Technology and Business Centre
Leamington Spa

New Members

We welcome the following new members:

Alice Carter
Reading
Region 1

Diane Ousby
Appleby
Region 9

Fay Cookson
Loughton
Region 5

Jane Burrell
Yeovil
Region 4

Jeff Smith
Ipswich
Region 5

Karen Wiltshire
Somerset
Region 4

Mary-Anne Rapson
Stoke
Region 7

Patricia Du Pontet
Taunton
Region 4

Stuart Reading
Bridgewater
Region 4

If you are interested in contacting the new members listed, please contact the relevant area coordinator, or the membership secretary, who can then supply the necessary contact details.

Useful Contacts

	Email	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218 184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
Simon Hubbard – Research co-ordinator	si@sjhubbard.com	01908 508 866
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 8853 4089
Della Brookman –Region 3 co-ordinator	della_brookman@msn.com	07710 637 941
Penny Cohen–Region 7 co-ordinator	pennycohen57@hotmail.com	07818 288 738
John Moore – Exec Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	johnmoore.9@btinternet.com	02392 592 784
Peter Bateman – Region 6 Co-ordinator (Wales)	sandra@peterbateman.co.uk	01656 788502
Adam Lawrence 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	adam@idios.co.uk	07834 505 161
Liz Redmond Neurogenetics Nurse	Redmond.liz@uclh.nhs.uk	02034 484 487